

King County Asthma Forum

Section 5 - Improving community awareness of asthma and KCAF programs and services

(Updated through March 2004)

Objective: Implement community organizing, coalition building, and community awareness activities to provide effective and sustained support to asthma care efforts in King County

Strategic Areas: Coalition effectiveness, community awareness

Description

Allies Against Asthma is carrying out community organizing, community awareness, and coalition building activities to support asthma care efforts in King County. AAA provides staffing for the KCAF Coalition and a health educator/community organizer to coordinate community efforts in the target neighborhoods.

Community Organizing. The most significant community organizing activity is the formation of four Neighborhood Asthma Committees (NACs) to bring parents and other community members into the work of KCAF and to launch local asthma projects. The first NAC was formed in January 2002 in the Rainier Valley and New Holly communities. NACs were then established in White Center, Burien, and South Park. The goals of the NACs are to provide education around asthma, increase support for families with asthma, develop leadership among NAC members, and develop small-scale projects chosen by the NAC members. The AAA Community Organizer/Health Educator works with leaders from each NAC helping them prepare an agenda for monthly meetings. Each NAC identified one or two members to attend monthly coalition Steering Committee meetings to increase grassroots participation in coalition governance and to help them understand how the NACs fit into the overall work of KCAF/AAA. These NAC members are 'bridges' between the Steering and Neighborhood Committees facilitating information flow in both directions.

Community Awareness. The AAA Community Organizer/Health Educator meets regularly with community-based organizations (CBOs) to promote awareness of asthma and identify ways that AAA can be supportive of ongoing efforts by the organizations. Recently, this outreach work expanded to include the three AAA Community Health Workers and often includes having an asthma booth at local health fairs or presenting information to community health clinics and schools in the target areas. Awareness efforts have served as a recruiting mechanism for the AAA home visit intervention. In addition, the KCAF/AAA website was recently revised with the intent of making the site more useful and user-friendly for community members. The site will serve as a substantial resource for community members and other professionals working in the asthma arena.

Coalition Building. AAA coalition-building efforts are focused on strengthening KCAF. The goals of the coalition development effort are to:

- Increase CBO and parent/child involvement in KCAF activities
- Increase participation of health plans and hospitals
- Expand coalition leadership
- Increase visibility of the KCAF and its activities
- Develop and implement a sustainability plan for KCAF
- Increase the number of projects affiliated with KCAF and increase resources and funding through grants, government allocations, and other funding sources

Progress

The primary process measures for the coalition effectiveness and community awareness efforts are the number of coalition, NAC and other community meetings and outreach activities as well as the number of community presentations made by AAA staff and volunteers. Outcome measures include member satisfaction with coalition functioning, increased community and minority representation and decision-making, development of sustainability mechanisms, new grants awarded to KCAF projects, and the number of projects affiliated with the coalition.

Process Measures

<i>Process objective</i>	<i>Status/ Indicators</i>	<i>Next steps</i>
Community Organizing		
Create and sustain active Neighborhood Asthma Committees	<ul style="list-style-type: none"> • 4 active NACs; meet monthly • Leaders identified, attend and report at monthly Steering Committee meetings • 2003: NACs met 44 times, 116 participants; 36 attended two or more meetings • 34 interactive self-management presentations to members 	Continue recruitment strategies
Community Awareness		
Make presentations to community-based organizations, clinics and schools.	<ul style="list-style-type: none"> • Number of presentations: 21 to community organizations and four presentations at the KCAF quarterly forum • Sectors reached: CBO's, schools, clinic 	Continue making presentations
Attend and participate in other outreach activities	<ul style="list-style-type: none"> • Number and types of activities: health fairs, 1NFL alumni event, school open houses, family nights • Held an asthma play at 3 locations for middle school students – 500 attendees • 1 media presentations - local radio talk show – 3 coalition members interviewed • Distributed flyers and posters to over 20,000 elementary schools and families in 4 districts and numerous community sites and clinics 	
Coalition Building		
Establish governance structure and bylaws	<ul style="list-style-type: none"> • KCAF coalition and Steering Committee governance structure established • Updated by-laws in 2003 	Continue to revise structure and bylaws as necessary
Hold regular KCAF Coalition and Steering Committee meetings	<ul style="list-style-type: none"> • 12 Steering and 4 Coalition meetings/year • Average attendance (2003): Steering - 15, Quarterly – 22 • New disciplines now represented on coalition: pharmacy, Medicaid managed care, public relations 	<ul style="list-style-type: none"> • Carry out strategies in public relations plan to continue coalition growth

Outcome Measures

<i>Outcome objective</i>	<i>Status/ Indicators</i>	<i>Next steps</i>
Community Organizing		
NACs carry out effective projects in their neighborhoods	<ul style="list-style-type: none">• Description, scope and impact of NAC projects (see narrative below for examples)	Focus on policy in 2004
Community Awareness		
Increase awareness of asthma by CBOs/other organizations and by community residents	<ul style="list-style-type: none">• Residents: exposure to community activities (from baseline CHW survey)• CBO's/other organizations: Key informant interviews (KII's)	<ul style="list-style-type: none">• Waiting for data• CBO KII interviews to be conducted in 2004

Coalition Building		
Strengthen KCAF as a coalition	<p>Member ratings of coalition effectiveness (2002 CSAS¹ survey):</p> <ul style="list-style-type: none"> • Adequate representation from key sectors - 42% no, 33% yes • Comfort with decision making process - 50% very comfortable, 46% somewhat comfortable • Main leadership entities - 38% coalition officers/committee chairs, 23% lead staff • Conflict resolution style - 66% open debate, 27% don't know • Fair decision making – 52% agree, 30% strongly agree • Influence on decisions – 50% some, 28% a lot <p>(2003 ratings): (waiting for follow up data)</p> <p>Member feedback on coalition satisfaction (KII's):</p> <p>2001 – Forum is broad and represents diverse stakeholders; good networking opportunities;</p> <p>2002 – People are committed, care and are congenial; sense of camaraderie; feel ownership and commitment to the work; this is an opportunity to build a strong effective movement</p> <p>2003 –</p> <ul style="list-style-type: none"> • strengths: strong committed leadership, mutual respect, responsive and open communication, consistent member attendance • weaknesses: concerns about leader burnout, decisions subject to health department policies, minimal paid staff to carry out activities 	

¹ Coalition Self Assessment Survey – conducted annually and implemented across all AAA sites by the National Program Office

Increase community/minority representation on coalition	<p>Ethnic/minority group rated most important group to add: 44% (2002 CSAS); _____ rated most important: x% (2003 CSAS)</p> <p>Member feedback on community representation (KII's):</p> <p>2001 – Need to develop more effective outreach strategies; many are unsure of how culturally competent Forum is; lacking diversity</p> <p>2002 – Need to increase awareness within community and get more grass roots involvement; not enough diversity – both culturally and professionally</p> <p>2003 –</p> <p>challenges: difficulty achieving grass roots involvement</p> <p>successes: developed recruitment strategies that successfully increased community participation</p>	Waiting for follow up data
Increase community voice in decision-making	<ul style="list-style-type: none"> • Average # NAC members attending Steering Committee meetings: 2 • NAC members attending Steering Committee meetings communicate Forum issues with NAC members and then bring members opinions back to Steering Committee 	
Develop mechanisms for sustainability	<ul style="list-style-type: none"> • Sustainability plan in place and priorities identified for 2004 • Progress toward implementing plan (see below) • Grants/funding received (see below) • Developed draft public relations plan and KCAF logo • Formed new public relations/sustainability committee and hired a PR firm to lead PR plan development through a Department of Health grant 	
Increase number of projects that are affiliated with coalition	<ul style="list-style-type: none"> • 1 Core project , 3 Sponsored projects • Over 30 Endorsed projects • Description of resources generated (see below under successes for listing) 	

Successes, Challenges, and Lessons Learned

Successes:

Community Organizing

- **Four Neighborhood Asthma Committees** were established that bring residents together to talk about their concerns and to take on an asthma project specific to the needs and interests of each particular community
- **During the NAC planning stage many different perspectives, including the community voice, were heard and incorporated into the intervention.**
- **3 NACs have initiated local projects.** Rainer Valley/New Holly worked with three local summer camps to help them launch counselor training on asthma. They also held a World Asthma Day event at Aki Kurose and 90 students participated in a "What is Asthma?" poster contest. The South Park NAC also had a World Asthma Day event. They had a poster competition and they displayed at Concord Elementary. The Burien NAC hosted an "Asthma Wheel of Fortune Night" at Hazel Valley Elementary with about 80 participants. They are pursuing having summer camp counselor trainings and are contacting the Southwest Boys and Girls Club to make arrangements. White Center is establishing itself and has not yet selected a project.
- **The Community Organizer created a Speaker's Bureau that draws from coalition membership.** Topics offered are diverse and through the discussions, NAC members have become more educated on asthma issues. They are also learning self-advocacy skills. NAC members stated that these speakers are effective and succeeded in changing community member attitudes and knowledge levels.
- **NAC families formed supportive relationships** with one another and found information sharing helpful in the daily struggles caring for their asthmatic children.
- **Leadership skills among community members were strengthened.** In 2002 NAC leaders participated in a Tools for Schools training in Washington, D.C., and in 2003 one NAC member presented information about the NACs at a national conference (Society for Applied Anthropology) in San Francisco.
- **NAC members are being referred into the Community Health Worker intervention,** and vice-versa.
- **Community members attend Steering Committee meetings as voting members.** Since February 2003, NAC members have attended and participated in monthly Steering Committee meetings. With orientation and assistance from the Community Organizer/Health Educator, NAC members are learning about and participating in the larger work of KCAF and AAA, and are able to then report back to their respective NACs. In this way a feedback loop between the community and the Steering Committee is being established.

Coalition Building

- **Funding opportunities were pursued and awarded** (see table below).

Grant/Project	Description/Notes	Start/End Dates	Total Amount
Awarded:			
HH2	HHII is a research project of Public Health-Seattle & King County that is funded by the National Institute of Environmental Health Sciences. HHII's goal is to compare two approaches to improving asthma control: 1) providing patient education, training in self-management, development of a patient-specific asthma action plan, and case management review by an asthma nurse; and 2) providing the above, plus in-home outreach, education, and resources to address environmental triggers.	10/01/01-9/30/06	1,955,839 (includes indirect)

HUD Better Homes for Asthma	This 3-year research project will provide structural housing remediation for conditions that increase exposure to asthma triggers with the intention of lowering exposures and improving health status among children with asthma.	4/15/02 - 4/14/05	998,617 (includes indirect)
ACT	ACT is an educational program of the Allergy and Asthma Foundation of America- Washington State Chapter, and funded by the Centers for Disease Control and Prevention. The program provides a series of 3 educational sessions for children with asthma between 7 and 12 and their caregivers. The program is conducted in English and held at community clinics or community-based organizations.	10/1/03-10/1/04	\$135,000
EPA Asthma Training and assessments	Supporting asthma training for childcare providers and follow-up indoor environmental assessments and education	10/1/03-10/1/04	\$20,000
Seattle Housing Authority	Building healthy homes in public housing units for people with asthma. Conducting indoor environmental assessments and trigger reduction education at public housing sites.	10/1/03-9/30/07	\$900,000
Washington DOH	For mentoring other coalitions and developing a public relations plan;	7/1/03-12/31/03	\$10,000
STEPS to a HealthierUS	Healthier STEPS is a CDC grant to provide support to communities to address multiple chronic diseases and related conditions, including: diabetes, asthma, obesity, nutrition, tobacco, and physical activity.	10/1/03-9/30/08	Asthma interventions: \$300,00/year
Applied for:			
HRSA Healthy Tomorrows Partnership	Improve the health, safety and well being of low income families with asthma attending Health Start/ECEAP/family child care centers in the central Seattle and southeast King county area through a collaborative approach to providing culturally competent, no-cost health education and affordable health care.	Not awarded.	\$50,000

- Revisions to KCAF governance structure, formalization of communication processes, and development of new committees** – KCAF has a well-developed governance structure defined by periodically updated by-laws. As the Forum evolves, its committees have also adapted to better fit the direction it is taking. In addition, ad-hoc committees were developed that have served valuable functions. A Cross Project Coordination ad-hoc committee formed to help coordinate and increase communication among Forum projects and in 2003 it became a standing meeting within the governance structure. It has since evolved into a formal standing committee. A public relations committee was organized to develop a PR plan. The community outreach committee no longer meets because their function is now met by the work of the Community Health Workers within the

AAA project. The Governance ad-hoc committee made sure that bylaws were modified so that they reflect the governance processes being used by Forum and Steering Committee members and move the work forward in an organized and meaningful way as the Forum evolves. [Click here for KCAF Bylaws](#).

- **Number of members and services affiliated with the Forum expands.** KCAF now has 70 members and 178 people in the communication network. Asthma projects occurring within King County have been recognizing the value of KCAF affiliation and have actively sought out an association with the Forum. In order to better define a project's affiliation to the Forum, three levels were developed and include "core", "sponsored", and "endorsed".
- **An asthma play was developed and held to raise awareness of asthma among middle school kids.** The play was identified as an important activity by one of the NACs. It was developed with input from the NACs and kids with asthma. 500 students attended and it will be offered again in 2004.
- **A KCAF sustainability plan was developed, top priorities were identified at a planning retreat, and a forum logo was adopted.** A standing public relations/sustainability committee was formed and will carry out the plan. With assistance from the Washington State Department of Health, KCAF has begun work with a public relations consultant to more effectively convey key messages in the community.
- **There is growing local and national recognition of KCAF** as leader in asthma coalition development. KCAF members have been keynote speakers at meetings held by the Centers for Disease Control, National Heart Lung and Blood Institute, and the New York City Asthma Partnership. They have also taken a leadership role in The Washington Asthma Initiative and entered into a mentoring relationship with other asthma coalitions in the state.
- **Entered into a mentoring relationship with other state asthma coalitions.**

Challenges:

Community Organizing

- **Increasing the number of new NAC participants.** NAC participation remains relatively stable at each location. The emphasis has been mostly on maintaining existing members, but it is anticipated that as each NAC takes on community-based projects attendance and participation in monthly meetings will increase.
- **Having enough resources as NACs evolve.** Staff were stretched to accommodate start up, building, and maintenance of four NACs and meal provision at every meeting requires significant funding.
- **Empowering community members to develop advocacy and leadership skills** so that they can take on issues within their community.
- **Establishing linkages between NACs.**

Coalition Building

- **Increasing professional and ethnic diversity** of Forum and Steering Committee.
- **Building new KCAF leadership.**
- **Developing ongoing sustainability strategies/mechanisms** requires broad member participation, which takes time and slows the process down.
- **Generating funding for coalition infrastructure.**
- **Ensuring that information and materials are understandable** for those that speak English as a second language.
- **Creating more awareness about NACs** within the local provider community.

Lessons Learned:

Community Organizing

- **Stipends are helpful for getting community members to the table.** NAC member participation on the Steering Committee increased when we were able to provide a stipend to help reimburse for time away from the job.
- **Need to be sensitive to time commitments.** Professionals often have an ideal of what "community participation" means, but often people in the community don't have the time, luxury, or interest in taking on leadership roles.

- **It takes a long time to develop a functioning Neighborhood Asthma Committee**, and continual staff support to oversee such items as location, agenda and food are needed.
- **Leadership takes time to develop** and an active and planned approach is needed.
- **The participatory approach to planning** creates satisfaction and allows for the incorporation of multiple perspectives.
- **Create opportunities that bring NACs together for information sharing, problem solving, and general support.**
- **Planning and assessing community needs takes time.**
- **During planning consider how resource requirements** might change as implementation occurs.
- **Having outreach presenters that share information** about a variety of topics effectively engages and informs participants.
- **Developing and funding innovative recruiting strategies** is challenging but critical to growth and sustainability.
- **Check progress along the way** to assess whether activities are meeting initial expectations.

Coalition Building

- **A coalition is required to develop the linkages** for carrying out a complex project with multi-level interventions. It can help develop a shared project vision, coordinate activities, and get participation of all necessary sectors/stakeholders.
- **Coordination of member activities is critical and rewarding.** It also takes time and an explicit process. KCAF has developed a cross-project coordination committee, specific cross-project referral protocols, and a central referral telephone center.
- **Coalition development requires staff support and other infrastructure support**, e.g. space, communications resources, capacity to host meetings. Short-term grants (e.g. 4-5 years) are not the best source of funds for this.
- **Need to reach out beyond “comfort zone”** to pull in under-represented sectors such as health plans and larger institutions.
- **In order to be effective, outreach must be ongoing and made a priority.**
- **People at all levels (caregivers and professionals) should have a say** in how they want to participate and what they want to receive from and contribute to the coalition.
- **Alternative methods for obtaining feedback and participation** that go beyond meetings need to be developed because decisions are often made in venues that don't attract a lot of community participants. Having alternative ways to get their participation and input (e.g. focus groups, community meetings) can add integrity to the decision making process. This is also true for providers and busy CBO staff. An investment in email communication, phone calls, visits, and other communication channels is important.
- **Avoid "overcommunicating";** there is a fine balance between keeping people on the coalition informed and information overload.
- **Share access to resources as widely as possible within the coalition** (especially funding opportunities)
- **Fiscal/administrative agents must be willing to cede decision-making authority** for grants that are based in a community coalition to coalition even though the agent is accountable to the funding agency
- **Sustainability often takes a backseat to more urgent issues** although pieces of it may be addressed regularly (such as grant writing)
- **Encourage members to support fellow coalition members.** For example, public health staff helped CBO members in grant writing and evaluation. CBOs have shared educational resources and developed new projects in partnership.
- **Having a coalition increases competitiveness when applying for grants** and enhances the credibility of members in their fund-raising activities.
- **Develop communication networks between local health care providers, community resources, and the NACs** so that providers and other community resources can refer their clients to NAC meetings.
- **Continue exploring and developing strategies that will increase coalition attendance.**
- **Ensure that interpreters are available at meetings** and that information, resources, and promotional materials are translated.